

Special Health Services (SHS) Family Advisory Council Meeting Microsoft Teams (Virtual) May 2, 2020 (1:30pm-4:30pm)

Attendance:	
Family Advisory Council Members	Moe Schroeder, Victoria Johnson, Sarah Carlson, Liv Fetterman Berger, Kimberly Ilse, Garrett Schultz
SHS Division Staff	Kim Hruby, Tina Feigitsch, Joyal Meyer, Amy Burke, Danielle Hoff, Heather Kapella, Jaime Conmy
Welcome and Introductions	The Special Health Services (SHS) Division Director, Kim Hruby, provided a warm welcome and relayed appreciation for the time devoted for the Family Advisory Council (FAC) meeting and the commitment made by participants to assist the division in its work throughout the year. Introductions were made and new member, Kimberly Ilse, was welcomed.
Last Meeting Follow-Up and Approval of Minutes	<u>Review and follow-up items to be addressed from last meeting on January 11, 2020.</u> <ul style="list-style-type: none"> • All recommended items have been in progress or completed. <u>Minutes and Recommendation/Review Summary from January 11, 2020.</u> <ul style="list-style-type: none"> • Liv motioned to accept the minutes. Victoria seconded the motion. Motion unanimously carried to accept the meeting minutes as written.
Medical Advisory Meeting Update	<ul style="list-style-type: none"> • No conditions were added to the eligible condition list • Statistical reports were discussed regarding number of children serviced. Numbers may increase as the Financial Program was moved into the state office. Reports will look very different next year with this change. • SHS does a lot of gap filling for children with no insurance or inadequate insurance. SHS is seeing more kid with unknown insurance status. • There are more children (around 11 children) getting closer to meeting the maximum of the

	<p>\$20,000 limit per year. One did reach that limit this last year.</p> <ul style="list-style-type: none"> • There are more referrals coming into SHS. Diabetes, Cardiac, and GI tract anomalies are leading in the high costs of children. • SHS and partners submitted a SFN 905 form to request continuous glucose monitor (CGM) coverage by Medicaid as SHS is currently the primary coverage for the CGMs.
COVID-19 Response Efforts	<p>Kimberly discussed SHS COVID-19 response effort activities that were being implemented within various programs within the Division including but not limited to:</p> <ul style="list-style-type: none"> • Coordinated Services Program: canceling/rescheduling Cleft Lip and Palate Clinics • Metabolic Food Program: ensuring all families have access to metabolic food and formula • Cardiac Care for Children: addressing any questions or concerns from families or providers • School Nursing: working with school nurses and DPI on guidance and answering questions • Newborn Screening and Follow-Up Program: ensuring there is no disruption in services provided • Financial Coverage Program: moving to virtual/phone applications with families; electronic claims <p>Discussion was had on COVID-19 and how it affects CSHCN and their well-being. Some healthcare facilities are letting parents/guardians in with their child, but that isn't always the answer that is received. If tools are able to be shared with families and provide them some reassurance, that would be helpful. A lack of PPE and other essential products is an issue as well for children and their families, so a long-term advocacy plan is necessary.</p>
Budget Update/Discussion	<p>General recommendations from the Governor came out yesterday. The Department of Health will be asked to make reductions, so SHS will wait to hear from fiscal staff to know what that means for each Section and Division.</p> <p>Kimberly asked the group what SHS could do differently or potential cost-saving efforts that SHS needs to look at. There were no recommendations from the group at this time. They will wait to hear when more specific information is released. Dr. Connell brought up getting the SFN 905 forms accepted by Medicaid could help decrease costs. Due to the economic issues, SHS may be gap filling for more children, so SHS will need to prepare to do more with less. Contracts to other agencies can be looked at</p>

	as a possible avenue to address budget cuts.
MCH Block Grant Application	<p>Kimberly discussed that the MCH Block Grant review process has changed due to the COVID-19 pandemic. This year the application will be due by September 15, 2020 and the review will be virtual and will take place on October 1, 2020. This provides more time to work with partners and develop workplans. If any members want to be a part of the review process, contact SHS.</p> <p>The 5-year Needs Assessment along with the new priorities that Title V will be focusing on for the next 5-year cycle. SHS will be focusing on the priority of "Transition to Adult Health Care". Heather discussed the various approaches that will be built into the workplan (systems, provider, and family approach). Moe brought up how transition has been addressed in the past and brought up challenges they faced. It was mentioned that a small curriculum could be developed and provided during health classes. Danielle welcomed any feedback or suggestions on the transition workplan that was shared as an attachment.</p> <p>It was brought up that it is important for providers to talk to the child, not the parents at their appointments. If children are unable to verbally communicate, independence can still be addressed in various other ways.</p> <p>Discussion was had on how it is hard when physicians are focused on so many other factors that comes overwhelming for providers. Perhaps looking to tie transition into reimbursement could be a strategy or connecting it to well-child checks. In addition, having transition be material for providers when they are recertifying.</p>
Administrative Items	<p>Membership terms up:</p> <p>Sarah Carlson: will renew term</p> <p>Moe Schroeder: will renew term</p>
SHS/NBS Program Updates	<p>Joyal provided an updated on the NBS program. NBS Program received an 18-month Continuous Quality Improvement grant. Will be working with the ND Health Information Network (HIN) to enhance interoperability between systems for NBS (vital records, OZ hearing system, HIN, Iowa database, Maven</p>

	<p>database, etc.) so information can flow from one system into the next. Want the ability to share data with providers and families to enhance the system of care. Three goals with this project:</p> <ul style="list-style-type: none"> ○ Build an IT Care Coordination Case Management system for long-term follow-up ○ Create system to reduce loss to follow-up with patients with positive newborn screenings ○ Revise education materials including all components of NBS (bloodspot, hearing and critical congenital heart disease). <p>Joyal and Amy are revising their brochure to include CCHD and hearing since the old brochure only contains bloodspot. They may reach out to families for feedback on the brochure. Amy also sent out a virtual survey to gather feedback on the welcome cards that are sent out.</p> <p>Amy and Joyal asked the group to reach out to them if they are aware of major concerns that would be helpful to include in the quality improvement project.</p> <p>Garrett Schultz stated he was willing to help out with NBS quality improvement projects as a family advocate.</p>
Closing Remarks/Wrap-Up	<p>Kimberly asked the group for permission to electronically sign and submit their \$75 stipend to accounting. This would alleviate the back and forth between members and state staff. The group was ok and granted permission to Kimberly to submit their forms on their behalf to accounting.</p> <p>Kimberly asked the group how the virtual meeting went. It was discussed to have the January meeting virtually and the rest of the meetings in-person. It was also brought up that it would be nice to have all meetings virtually and one in-person. It can be looked at to provide the option of joining in-person or virtually for all the meetings.</p> <p>It may be helpful for Garrett to connect with Kim as she is new to go over some of the background and being a mentor. Moe also suggested she could help as well. Kim will see how September goes and if she is overwhelmed, then the connection can still be made.</p>

	<p>SHS staff will talk and make a decision as a team and reach out for feedback on the group regarding the future platform for meetings.</p> <p>Next meeting is scheduled for September 19, 2020 and as of now it is an in-person meeting. It would be helpful to go through some of the history of SHS and the FAC for new members at this next meeting. Perhaps every fall meeting this can be done.</p> <p>Kimberly thanks the group for their valuable feedback and time they provide this council.</p>

SHS Family Advisory Council Recommendation/Review Summary

Meeting Date	Advice and Follow-Up	Action Taken
May 2, 2020	When developing the upcoming year's plan for activities, looking into tying transition into reimbursement or connecting it to well-child checks.	For the upcoming year, SHS will be providing education to medical providers regarding Bright Futures guidelines on transition and adolescent health well-visits.
	Consider holding the September FAC meeting virtually rather than in-person.	Kim will work with our administrative assistant to change this meeting to a virtual format rather than in-person.
	Consider utilizing members from this council as family advocates for topics such as newborn screening.	Family Advisory Council members have been asked to share their story at each meeting and at opportunities such as conferences.